

THE NATIONAL OVARIAN CANCER PROGRAM



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Background

Ovarian cancer is the leading cause of death from gynaecological cancers in Australia. In recognition of the impact of ovarian cancer on Australian women, in September 2001 the Federal Government committed \$500,000 over two years, to improve the health outcomes for women with ovarian cancer. The National Breast Cancer Centre (NBCC) was chosen to manage a national ovarian cancer initiative.

In November 2001, a strategic plan, *Priority actions for ovarian cancer control: a framework for a national approach*, was developed by an Interim Ovarian Cancer Steering Group, based on input from key stakeholders in ovarian cancer control. The plan outlined eight objectives, and from these objectives a work plan for the Ovarian Cancer Program was developed, focussing on a number of priority areas:

- Information for women, health professionals, policy makers and the community about aspects of ovarian cancer such as risk factors and diagnosis of ovarian cancer;
- Promotion of optimal management of all women diagnosed with ovarian cancer;
- Strengthening the provision of psychosocial, physical and practical support for women diagnosed with ovarian cancer and their families;
- Developing a national monitoring system for ovarian cancer control in Australia; and
- Encouraging all organisations concerned with ovarian cancer control to work collaboratively to improve ovarian cancer outcomes.

A multidisciplinary Expert Advisory Group was established to guide the work of the Ovarian Cancer Program. The work of the Program is also supported by a number of working groups for specific projects.

This report provides a summary of those objectives and the achievements to date.

Risk factors for ovarian cancer

While much research in Australia and internationally is directed at understanding the causes of ovarian cancer, there are currently no opportunities for community-wide prevention programs. Known risk factors include family history¹, age² and previous personal history of ovarian cancer. Pregnancy and oral contraceptive use are associated with a reduced risk of ovarian cancer³. Prophylactic oophorectomy⁴, tubal sterilisation and hysterectomy⁵ have been shown to reduce a woman's risk of ovarian cancer.

To date, the Program has commissioned a detailed review of the research about known risk factors for ovarian cancer and opportunities for prevention. The review will be made available in early 2004 and will provide an evidentiary base for the development of information for clinicians and women.

Information for women with a family history or known genetic risk for ovarian cancer

Up to 10% of all cases of epithelial ovarian cancer are thought to be due to hereditary factors⁶. Women with a genetic mutation in BRCA1 and BRCA2 have a risk of between 15% to 66% of developing ovarian cancer by the age of 70^{7,8}.

In association with the Genetics Expert Advisory Group of the National Breast Cancer Centre, and in light of recent progress in the understanding of this area, the published advice about familial aspects of ovarian cancer has been reviewed, with a view to simplifying the risk categories.

Encouraging prompt diagnosis for women with symptoms that may be ovarian cancer

It is estimated that about 70% of ovarian cancers are advanced at diagnosis¹ and advanced disease has a poor prognosis. It is difficult to diagnose ovarian cancer at an early stage because early disease is typically asymptomatic, early symptoms are non-specific and there is currently no accepted method for population screening.

In progressing activities in regard to this objective, the Expert Advisory Group has agreed that there is currently no evidence to support the conduct of a public education campaign about symptoms of ovarian cancer. The group is developing guidelines for general practitioners to assist them with the often difficult assessment and investigation of women who may have ovarian cancer.

Promoting optimal management of all women diagnosed with ovarian cancer

The five-year relative survival of women with ovarian cancer after diagnosis is about 42%⁹. Adverse prognostic factors for ovarian cancer include older patient age, later stage of disease, higher tumour grade, presence of ascites and residual disease.

Most Australian women with ovarian cancer are treated with surgery and/or chemotherapy. There is some evidence that women with ovarian cancer who are treated by a gynaecological oncologist have improved survival rates^{10,11}, yet a large number of women do not currently receive optimal care.

To address the lack of national evidence-based guidelines about the management of ovarian cancer, the Australian Cancer Network established a working party in 1999 to develop the *Clinical practice guidelines for the management of women with epithelial ovarian cancer*. This process has been subsequently supported and completed under the auspices of the Ovarian Cancer Program and the guidelines have been submitted to the National Health and Medical Research Council (NHMRC) for approval. The guidelines will be disseminated nationally during early 2004, followed by initiatives to promote the benefits and improved outcomes of multidisciplinary care of women with ovarian cancer.

Research conducted in Australia and overseas indicates that outcomes are improved for women with cancer who are informed about their treatment options¹⁰. Women with ovarian cancer seek information about a wide range of topics to help them understand and deal with their diagnosis. A consumer guide for women with ovarian cancer is being developed by the Centre, based on the evidence in the *Clinical practice guidelines for the management of women with epithelial*

ovarian cancer. The guide will address topics such as the types and stages of ovarian cancer; treatment options; managing pain and side-effects; the use of complementary and alternative therapies; and support issues.

Strengthening the provision of psychosocial, physical and practical support to all women diagnosed with ovarian cancer and their families

The diagnosis of ovarian cancer has a major impact on women and their families. Of women diagnosed with ovarian cancer, a high proportion has advanced disease¹. Therefore, providing adequate support for women to improve their quality of life is an important component of patient care. Adequate support and information can improve cancer patients' wellbeing, quality of life and satisfaction with care¹². Good communication skills, information provision and continuity of care have also been found to improve quality of life for cancer patients¹².

Currently, there is limited access to supportive care services in Australian gynaecological oncology units. The Ovarian Cancer Program is working with the Psychosocial Expert Advisory Group of the National Breast Cancer Centre to investigate the specific needs of women with ovarian cancer and to develop strategies for addressing these needs.

National monitoring system for ovarian cancer control in Australia

While some data are collected about ovarian cancer in Australia, there is inconsistency in the way that data are collected and reported. This makes comparison of data between states difficult. Regular and timely monitoring of ovarian cancer control will enable the targeting of new programs and the evaluation of the effectiveness of current programs. Such a monitoring system should be comprehensive including data about incidence, mortality, diagnosis, treatment and supportive care needs of women with ovarian cancer.

The Ovarian Cancer Program has developed plans to review national data about ovarian cancer and data collection processes to identify gaps in the information available and to direct the development of a strategy to standardise data collection about ovarian cancer.

To provide all women, health professionals, policy makers and the community with access to current, accurate and appropriate information about all aspects of ovarian cancer

Women, health professionals, policy makers and the community should have access to accurate, appropriate and timely information about relevant aspects of ovarian cancer control.

The Program has acted as a clearinghouse for evidence-based information through: a monthly electronic newsletter (*Ovarian e-upd@te*) disseminated to clinicians, researchers, consumers, cancer councils, state and federal health departments (12 issues to date); and through the establishment of a website for the Ovarian Cancer Program (www.ovariancancerprogram.org.au).

To encourage all organisations concerned with ovarian cancer control to work collaboratively

There are many groups working towards improving ovarian cancer control in Australia. Collaboration between these organisations is vital to improving outcomes for women and maximising the use of resources by avoiding duplication and by introducing varied expertise.

The Ovarian Cancer Program has built relationships to foster a collaborative approach through the establishment of a multidisciplinary Expert Advisory Group to provide advice about the projects and through contact with a range of clinicians, researchers and consumer groups involved in ovarian cancer control. A national ovarian cancer forum, planned for early 2004, will bring together key stakeholders from relevant areas in ovarian cancer control and foster a national information network. It will provide a further opportunity to promote multidisciplinary care and will focus on the delivery of health services and opportunities to improve outcomes.

In summary, the national Ovarian Cancer Program has been active in a broad range of areas. The Australian Government has provided additional funding until the end of 2003, and this will allow further development of these initiatives. With the recent re-funding of the National Breast Cancer Centre for a further four years, the Ovarian Cancer Program is seen as an integral component of the Centre's future work plans.

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